View metadata, citation and similar papers at core.ac.uk

brought to you by CORE

provided by Elsevier - Publisher Connector

Journal of the American College of Cardiology Vol. 56, No. 23, 2010
© 2010 by the American College of Cardiology Foundation
Published by Elsevier Inc.
ISSN 0735-1097/$36.00
doi:10.1016/j.jacc.2010.11.008

EDITOR'S PAGE

Problems With Immortality

Anthony N. DeMaria, MD
Editor-in-Chief, Journal of the American College of Cardiology

Although immortality is, I guess, one of the ultimate goals of medicine, no human has thus far achieved it, nor is anyone likely to do so for the foreseeable future. However, the same is not true for human tissue. I recently read a book about Henrietta Lacks (1), the woman whose cancer provided the HeLa cell line that has thus far proved immortal and has been responsible for many fundamental scientific breakthroughs. Although these cells and the discoveries they have enabled are a cause for celebration, they have also been representative of a number of problematic issues in medicine, many of which remain unresolved. In fact, some of the issues may be even more prominent today as we strive to develop stem cells and achieve tissue regeneration.

Henrietta Lacks was a poor African-American woman living in Baltimore who developed a very malignant carcinoma of the cervix at a young age. The cells from this tumor were taken, for all intents and purposes without her knowledge or consent, and sent for possible tissue culture at Johns Hopkins University. They proved to be the first "immortal" human cells capable of forever continuously reproducing when cultured outside of the body, enabled many medical advances, and also became a profitable commercial product. Today, HeLa cells can be found in laboratories throughout the world, and they continue to be the cornerstone of a large body of medical research.

The first aspect of the HeLa story that struck me, as it might most clinical investigators, was the serendipity of discovery. George Gey, the Hopkins researcher who grew the cells, had been unsuccessfully trying to culture human cells for many years. He had experimented with a myriad of culture media recipes without success. In fact, there was nothing unique or special about the media in which he placed Henrietta Lacks' cells in comparison to that used for many other cells that did not reproduce. The "discovery" was the result of the good fortune of obtaining cells that were almost indestructible. It is amazing to think of how many critical medical discoveries have depended heavily upon chance. However, it is also true that luck leads to important discoveries when it encounters the prepared mind. Henrietta's cells were absolutely unique, but they would have gone undetected and unrecognized had not George Gey been looking and been irrepressible in his search.

A perhaps weightier issue regarding the HeLa story relates to the socioeconomic status of the donor. Henrietta Lacks was a poor woman with little formal education who came under the clinical care of a research medical institution that provided safety net treatment for the uninsured. Although less prevalent today, this arrangement was fairly typical of the times (1950s to 1960s). So, the lower socioeconomic classes typically contributed disproportionately to the pool of research patients. Patients were sometimes uninformed about investigation, much less asked for their consent. We have long since rejected any such notions, and many of the courageous and altruistic patients who participate at uncertain risk in clinical trials now come

Perhaps the most problematic, and still largely unresolved, issue raised by the HeLa story concerns the ownership of tissue once it is removed from the body.

from middle and upper socioeconomic classes. Nevertheless, this was probably not a proud moment in medical history, and today there still remains a bit of a divide in early stage research participation between patients and physicians in private hospitals and those in academic medical centers.

Neither Henrietta nor her family knew that her cells had been taken for research and were financially valuable until some time after her death. The issue of informed consent has now been well addressed in the United States. In fact, some would say it has perhaps gone too far. Approval is now often required for activities that could not constitute either risk or financial benefit to the patient. Nevertheless, it is probably better to do too much than too little. It is startling, however, to see the change in attitudes in the last several decades, and to realize that only a short time ago research was performed without the knowledge or understanding of the subjects.

Perhaps the most problematic, and still largely unresolved, issue raised by the HeLa story concerns the ownership of tissue once it is removed from the body. Selling Henrietta's cells ultimately provided a profitable business opportunity although Dr. Gey and Hopkins gave the cells away for free. However, neither Henrietta nor any of her relatives have ever received a penny of income. Among the questions raised is whether an individual has to be informed that tissue removed from his or her body may be used for research and has to consent to this use; the answer is apparently no. I must admit, I have had blood drawn for tests many times, but I have never wondered where the specimen has gone, and certainly never considered that it might be used for research. But, it appears that is entirely possible; we legally lose all ownership of our body parts whenever they are removed from the whole. The ancillary issue is who should benefit if the tissue leads to a profitable commercial business. At the moment, the answer seems to be that the patient has neither a right nor recourse to any financial gain from the tissue that he or she provided for the research.

The above issues of informed consent and financial gain are controversial and are the subjects of considerable ongoing debate. As a patient, I instinctively feel that, if it is my body, I should own the part, should certainly be informed if and how it will be used, and should share in any financial gain. This certainly seems to be true for all of our other worldly possessions. Although it is logical that we have a strong responsibility to do what is best for society with our tissue, this does not apply to other possessions such as money or property. Those opposed to this concept (not surprisingly, primarily the scientific and medical industry community) contend that the general rules governing the conduct of clinical research already provide adequate protection for the rights of patients regarding their tissues. Importantly, they argue that our moral obligation to benefit society outweighs personal considerations, and that good health differs from other possessions in this regard. They point out the logistical difficulties in trying to give patients control of their tissues. The actual investigation the specimen is used for may occur many years after and for a problem unforeseen at the time of donation. Finally, those opposed to patient control worry that the potential of a financial benefit may lead to unrealistic demands and negotiations and, eventually, to the loss of important opportunities for medical advances. Of course, this applies equally well to the intellectual property rights that the scientific community values and utilizes.

While the issues relating to the control of removed biological material have always existed, they may be even more pressing in the future. Cardiac regeneration utilizing stem cells is one of the major thrusts of contemporary research. We have participated in several studies in which the evidence of immune protection of stem cells has been exploited to utilize donor cells for therapy. Prior to reading Skloot's book (1), I would not have thought to question the consent of the donors or their participation in any profits. In addition, the revolution in genetics/genomics has raised questions regarding the ownership of genes and genetic material. It seems clear that these questions will receive more rather than less attention as time goes by.

Rebecca Skloot has written a magnificent book (1), and one which raises important questions for us in medicine to address. We are walked through the serendipitous discovery of "immortal" cells at Hopkins, and we wonder how many other similar tissues were discarded due to the lack of interest of those in charge. As the saying goes, those who work the hardest often have the most luck. We are once again reminded of the crucial importance of our patients to our research; they are the real heroes. As for the ownership of biological material removed from the body, I am ambivalent. It seems absolutely reasonable that patients should have a say in whether and how their tissues might be used, and share in any profits that might result. While it might be an unearned gift to have tissue of great value, the same could be said for great intelligence, or a great

JACC Vol. 56, No. 25, 2010
December 14/21, 2010:2140–2

voice or athletic ability, and so on. On the other hand, if a tissue had the potential to provide a cure for cancer, I cannot see how the rights of the patient could outweigh the potential benefit to society. We have given government the right of eminent domain to acquire real estate, so surely we could do the same for biological material. As in all things in medicine, we as physicians should take the lead in resolving these dilemmas. Although immortality remains an elusive and presumably extremely desirable goal, it is clearly not without its problems.

Address correspondence to:
Dr. Anthony N. DeMaria
Editor-in-Chief, *Journal of the American College of Cardiology*
3655 Nobel Drive, Suite 630
San Diego, California 92112
E-mail: ademaria@acc.org

REFERENCE

1. Skloot R. The Immortal Life of Henrietta Lacks. New York, NY: Crown Publishers, 2010.